

Brushing Up on High-Quality Oral Health Care for Children with Medical Complexity

In this Complex Care Journal Club podcast episode, Dr. Robbie Dembo and Ms. Kate Honsberger discuss a mixed methods study of oral health experiences and disparities among children with special health care needs. They describe oral health problems faced by children with medical complexity, barriers to high-quality dental care reported by family caregivers, and strategies for disseminating findings from their study.

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Kristina Malik 00:04

Hello and welcome to the Complex Care Journal Club Podcast. My name is Kristina Malik, and I'm a pediatrician at Children's Hospital Colorado, and your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and implications for practice. I'm delighted to have Dr. Robbie Dembo and Kate Honsberger from NORC [National Opinion Research Center] at the University of Chicago, joining me today. They are the lead researchers of a mixed method study entitled Oral Health Among Children with Special Health Care Needs. The study results were presented in a live webinar and online. Robbie and Kate, thank you so much for being here.

Robbie Dembo 00:39

Thanks for having us.

Kate Honsberger 00:41

Yeah, thanks.

Kristina Malik 00:44

So we'd like to ask you to share a bit about your study, starting with the gaps you identified and your research aims?

Robbie Dembo 00:51

So we know that oral health plays a really important role in supporting children's overall health and well-being. It's associated not only with children's physical health, but also outcomes like school attendance and academic performance and psychosocial well-being. As a policy issue, improving oral health in children and dental care access among children are recognized as important public health goals. Oral health concerns are also particularly prevalent among children with special health care needs, which is a medically vulnerable subgroup representing about 20% of children aged 18 years and younger. Children with certain health conditions and disabilities commonly experience dental crowding, malocclusion, teeth clenching, grinding, craniofacial and other structural anomalies, which can all contribute to dental complications. We also know that children with special health care needs may have difficulty maintaining daily oral hygiene habits and special diets and medications required by some children can have side effects that contribute to cavities and periodontal problems. So, we know that there are heightened vulnerabilities for children with special healthcare needs with respect to their oral health, but despite this, it's not really a topic that has received a lot of attention in the research literature or in health policy agendas, broadly speaking. When Kate and I reviewed the literature on this topic, we came away with the conclusion that the field really lacks a comprehensive understanding of the oral health needs and dental care experiences of children with special health care needs, including comparisons among children with varying levels of medical complexity and among children with and without special health care needs. We also note that there has been little attention paid to subgroup differences or intersectional disparities. For instance, on the basis of race and ethnicity, social class and other aspects of social life, which we know in this country structure a large part of the variance in health and healthcare outcomes. So we received a grant in 2024 from the Lucile Packard Foundation for Children's Health to conduct a study which we're going to be talking more about, but at a high level the study had an aim to fill these gaps that I just described, and the overall goals of the project have been to first characterize the needs, experiences and disparities in oral health and dental care, including barriers to access among children with special health care needs. And second, to identify promising strategies to improve the

system of care and achieve a more equitable dental care system and equitable oral health outcomes for children with special health care needs.

Kristina Malik 04:33

Your study is a mixed method study, and part of your analysis included analysis specifically on children with medical complexity. So yeah, tell us a little bit about your methods that you used, why you picked mixed methods and then how you also studied children medical complexity specifically?

Robbie Dembo 04:53

Sure. So, as you mentioned, this was a mixed method study, so we kind of structured it into three pieces that fed into each other. The first was a quantitative study, and we used the National Survey of Children's Health, which is a national annual survey that's conducted by the Maternal and Child Health Bureau and administered by the Census Bureau, and it has a lot of rich information about children's oral health, including prevalence of oral health problems and utilization of preventive dental care. So we're able, in these data to ascertain both children with special health care needs using the CAHMI [The Child & Adolescent Health Measurement Initiative] screener, and also we used an approach published by Justin Yu a few years ago on ascertaining children with medical complexity using multiple domains that are identified by Cohen and folks, but we use that approach to construct a group of children with medical complexity. I can tell you that when we look at the data, the National Survey of Children's Health, and we compare children with and without special health care needs, and children with medical complexity as a subgroup of children with special health care needs, we see that there are significant differences in the prevalence of chronic oral health problems. You just see an increase in the prevalence of things like frequent or chronic cavities, tooth bleeding, and gum problems. And we also see something sort of paradoxical when we look at the utilization of preventive dental care, which is that among these different groups of children, there is a similar prevalence of utilization of preventive dental care, and in some cases, we see greater utilization of preventive dental care among children with special health care needs and medical complexity. Which poses a bit of a paradox for us in understanding what are the drivers of chronic oral health problems and disparities in oral health problems. It would suggest that access to preventive dental care or utilization of preventive dental care alone is not driving what we see in these differences in oral health, chronic oral health problems between these groups of children. So those are some of the high level findings.

Kristina Malik 08:05

So Kate, can you tell me a little bit about the qualitative portion of your study please?

Kate Honsberger 08:11

Yeah, I think we in addition to the quantitative analysis that Robbie shared, you know, we really were interested in hearing directly from parents and caregivers of children with special health care needs about their experiences navigating the dental care system for their children and also helping to maintain their oral health at home. And I think, you know, pairing the qualitative approach, which we conducted focus groups with the quantitative analysis really helped give us a fuller picture of what's going on as families try to navigate the system. So we conducted seven focus groups with parents of children with special health care needs. Two of those focus groups were conducted in Spanish, and they were monolingual, Spanish-speaking parents. We were really interested in seeing if those parents experienced similar or additional challenges navigating the dental care system for their kids. And so when we conducted these focus groups, we found that parents overwhelmingly said that they faced challenges, and they faced challenges in several different areas. So first, in just finding dental providers who were either willing or able to meet their child's needs. Parents felt like their dental providers didn't receive the training they needed to help care for children with complex needs. They also noted issues with things like even being able to physically access dental offices and exam rooms as being a challenge. So even if they found a provider who accepted their insurance, or they felt like was willing to see their child they then reported, you know, physical access challenges to even getting into the office or being able to access the exam room equipment. There was also, even outside of the dental office, parents expressed frustration with dental providers and feeling like they

weren't getting the tailored guidance that they needed on how to maintain their child's oral health at home. A dental exam is one day out of 365 days, and parents felt like they really needed support in helping maintain their child's oral health, you know, for the rest of the year. And so, parents said dentists told them, generic guidance that they might give any parent, make sure your child flosses, make sure they're brushing twice a day. And they didn't go the next step on telling them how, or give them strategies for how to do that, given their child's physical or behavioral limitations. So a lot of challenges, you know, finding dental providers, accessing the care they needed, and then also getting the tailored guidance they needed on how to maintain their oral health at home.

Kristina Malik 10:58

You've already published the results to accelerate dissemination of your practical findings. So you hosted a webinar, and you also have it on the NORC website. I was hoping that you could talk a little bit about your dissemination plan for your research and why you were starting with a webinar as your first step?

Kate Honsberger 11:16

Sure. As Robbie mentioned, this was a grant-funded project by the Lucile Packard Foundation for Children's Health, and as part of that grant proposal, we built a dissemination plan into our grant that was really designed to try and reach as many audiences as possible. And that's something that Lucile Packard as a funder, is really interested in this type of approach. We didn't want this research to just sit on a shelf. So, as you mentioned, we did a national webinar to share out the findings. We also documented our findings in a series of briefs, summarizing each component of the work. So the data analysis that that Robbie mentioned, we have a brief summarizing the findings from the focus groups with families that we did. We even translated the focus group report into Spanish, since we had those monolingual Spanish-speakers as part of the focus group research, we wanted to make sure that they were able to read the findings, and that anyone who speaks Spanish and reads in Spanish could access those findings. We also conducted an expert panel convening and summarized the findings from that. So all of that is on the NORC website. And we also made sure to share the summary of the focus group report with the participants themselves. So again, we wanted folks to see the results of their participation in the research process. And those were things that we prioritized getting out as soon as possible. You know, we kicked off this research project in January of 2024, and here we are, a year and a half later, sharing out the results. And so this approach really helps us move the policy conversation forward as quickly as possible and to help inform future research needs. We are currently working on a peer reviewed journal article so that's another kind of important audience. And we've also had, you know, we have plans for a roundtable presentation at this year's American Public Health Association annual meeting in the fall. And so really making sure we're sharing out the results in as many different methods to as many different audiences as possible was really important to us.

Kristina Malik 13:27

When I was on the webinar, you really gave a lot of practical things that clinicians can do today to make a change in the practice and help this population. I was wondering if you could talk a little bit about that pragmatic side of your results?

Robbie Dembo 13:44

Sure. So I think the first thing to say, just as a disclaimer, is that neither Kate nor I are clinicians, but we can share with you the findings and themes that we have learned as researchers from this study. The first is that there are a lot of system level challenges, including with insurance, challenges with finding providers that take Medicaid for instance, or struggles with having insurance cover anesthesia was a big concern that came up with parents in the focus groups. At a clinical level, a big theme of what we heard from families, as Kate mentioned, was a real frustration with the lack of individualized, tailored dental care and support. When families would be at the dentist with their child, they would receive guidance or instructions that they often perceive to be generic and that did not have the unique needs of their child in mind. And so an example we heard that Kate mentioned was this emphasis on flossing, where, you know, the parent would say to the dentist that their child could not tolerate having floss, you know, digging in between their teeth, rubbing on their gums, and this sort of lack of tailoring or

individualization on the dentist's part on, well, if flossing is important, how can we try to accomplish this in a way that the child would tolerate? So there's that type of adaptation in care, in guidance that families really felt was missing and that they yearn for. Another takeaway was this interest in having dentists to be a greater part of their child's care team and to reach out to the other professionals who are familiar with the child's needs to better inform the dental care that is being provided in the dentist's office. So often, these children, and particularly those with medical complexity, have many different providers that they're seeing, and many of these providers have a really profound relationship and understanding of the child's needs. And dental care is just a less frequent type of care, and so often families felt that dentists just did not have a deep understanding of their children's health situations. And so having a greater collaboration, communication, coordination between the dental providers and the rest of the care team is something that many families described that they would value.

Kate Honsberger 17:09

I think another thing that I remember from parents is wishing that dental providers were just a little bit more creative, that was a word that I remember parents sharing is, because of your child's needs, just thinking outside the box about ways to maybe complete a dental exam or complete a cleaning, not just business as usual. And so that might mean things like working with an occupational therapist or an ABA [Applied Behavior Analysis] therapist, or it might just mean making small adjustments to things like the exam room or the waiting room, or making small adjustments that that could have a really big impact on how a child is experiencing care and receiving care in a dental office.

Kristina Malik 17:55

Yeah, it really seems that the qualitative components really answer that paradox that Robbie first found in the quantitative study that you can have access to a dentist, but it's not the quality of care, the tailored care you really need.

Kate Honsberger 18:12

Absolutely we had one parent who talked about, you know, their child was a teenager, and she reported that, yeah, she was taking the child to dental appointments every six months, but the child was a teenager and had never received a complete cleaning. So that's a perfect example of someone who, yes, is checking the box of getting, you know, a preventive dental visit, but what's happening during that visit? Is it fully meeting their dental needs?

Kristina Malik 18:40

What is your message for patients and their families from this study? Did your interviewees have any insights on what can facilitate better care?

Kate Honsberger 18:50

I think listening, you know, that was the biggest part and taking the time, right? So there was a lot of desire from parents for providers not to just be thinking about their child's care as they walk in the door for the appointment, right? So taking the time before the appointment to get up to speed on, particularly for a new patient, getting up to speed on their medical history, approaching the appointment with ideas in mind about how to care for this child, given their unique needs. More time in the appointment itself. The clock is not going to start and stop, you know, for the same amount of time as a child without complex medical needs. And so, taking that into account, and again, that requires adaptation to processes and approaches, but the parents really felt like that's what was needed.

Robbie Dembo 19:40

Another piece that I would just add is that whenever you do any type of research, particularly using qualitative methods, but really any type of research with families or parents of children with disabilities or complex health care needs, there really is often a sort of a cathartic element to the parent participation in the research, to feel like

they're given a space and an opportunity to express, you know, how they feel, and to describe their experience as a parent with the challenges that they face. It's a very special and almost sacred type of conversation to have. And we really experience that in these focus groups, and I think that coming away from this study, something that I would just encourage families to try to pursue is, the purpose of this research was, was not to provide a therapeutic, you know, space that's sort of incidental to the study, but I would just encourage parents to seek out other groups of families who have a shared experience. And it can help, I think, troubleshoot and strategize around this topic, what type of, you know, equipment or products do families find effective in brushing their kids' teeth or flossing their kids' teeth? What type of strategies do they deploy when they go to the dentist's office? What type of arrangements do they make ahead of time with the dentist's office, before the appointment? You know, these are all learnings that families can share with each other, that I think are very valuable coming from other folks with a similar experience. So that's just something that I would encourage parents to seek out.

Kristina Malik 22:03

I mean, as a clinician, that's how I learn a lot about guidance for my families, is what families tell me works and I disseminate to my other patients. So I agree with you there. Can you tell me a little bit more about opportunities and challenges you identified while developing and conducting this study?

Kate Honsberger 22:24

Yeah, I think on the opportunity side, you know, we might sound like a broken record on this, but we've really felt like this kind of qualitative element of our research was really valuable in as a provider that cares for children with complex needs, I'm sure that that you see children and families that face challenges on a daily basis, but you know, that's just a collection of experiences from one provider and one clinical setting. And we really felt like there was an opportunity to collect information from kind of a wide range of parents. You know, it's not generalizable to every parent, but really helped allow us to hear about experiences across the country. We talked to parents in 20 different states. We talked to parents who lived in rural and urban areas, and we really prioritized making sure that the group of parents we talked to represented different races and ethnicities, different insurance types and who received dental care in a variety of different clinical settings. Some were going to specialty pediatric dental providers. Some were going to general dentists that were right down the street from their house. And so, you know, really understanding and talking to parents in all different kind of walks of life and who had had different types of experiences really helped us kind of better understand how widespread some of these issues are. So that was, one of the biggest opportunities taking what we had heard anecdotally from providers, and collecting data in a way that that helps us understand the issue more broadly. I will say that qualitative approach, while it presented a lot of opportunities, it also presented a lot of challenges that Robbie and I navigated in trying to reach, you know, the 40 or so parents that that we wanted to talk to for this project. So Robbie, do you want to share some of the challenges?

Robbie Dembo 24:15

Sure, so this has become a kind of lore among the other grantees of the Lucile Packard Foundation at this point, but we had an experience of recruiting for the focus groups where we worked with a trusted community partner that works with families and parents of children with special healthcare needs to help us to recruit participants, and somehow we had a screening survey to screen people to ensure that they would be eligible for the survey, that they fit with inclusion criteria that we were interested in for the study, and despite working with this trusted community partner, we determined that we received over 1000 likely fraudulent responses to the screening survey for our focus group recruitment. So that was not something that we anticipated, that was not something that we were prepared to weed through to try to identify who was a legitimate parent and who was posing as a parent who was a bot. So that was a big learning for us as far as the risks of qualitative recruitment, and we developed some tactics to moving forward how to better safeguard against that challenge. So that was a surprise, and something that we learned a lot from. And several of the findings, particularly the themes that we heard from parents about challenges with the care that they were receiving, the lack of individualization and tailoring does speak to a training issue for dental providers. The focus of this study was not on dental education, but that is

certainly a target for intervention, innovation, enhancing the curriculum to ensure that providers have a nuanced understanding of the varieties of special health care needs that can present in children. And we think that's just very important. You know, 20% as I mentioned, of kids, have special health care needs. So that's one in five kids who's going to be coming into your practice. So to have the education in how to support and provide care to that population is really critical.

Kristina Malik 27:27

What do you think the next steps from your work are, or what is your team working on?

Kate Honsberger 27:34

I think in the immediate short term, I mentioned we're continuing to disseminate these findings. So working on a peer reviewed journal article, working on conference presentations, to continue to share out these results. In our summaries of the findings from each of the components of the work, we have outlined areas where we feel like there's additional research needs. So we really saw this as a first step, as a understanding, you know, laying the groundwork for additional research. Robbie talked about the training needs that that we feel like we're pretty clearly, you know, outlined in in our initial findings. There were other aspects of the findings too that I feel like are kind of begging for, for additional work. So things like some of the systemic barriers around insurance coverage, and you know, what are some of the potential policy solutions for moving that forward? So things like coverage for sedation for children that need that approach for dental care, but also things like insurance coverage for, you know, at home dental care. We heard from families that it would be really helpful to have insurance cover things like specialty toothpastes or specialty toothbrushes and so the parents aren't having to pay out of pocket for that kind of thing.

Robbie Dembo 28:55

And the reason for that is because, due to the lack of specific instructions and guidance from providers, families are often going home and having to trial and error and experiment with products, as Kate mentioned, toothpastes that their kid can tolerate. Toothbrushes that child with sensory sensitivity can use, flossers. And often, we heard families describing spending hundreds of dollars on products where you buy a toothpaste, they use it once, the child can't stand it, it goes in the garbage. You can't return it, and so to have better coverage, to try to offset the really steep costs involved in the trial and error would be super helpful.

Kate Honsberger 29:58

Yeah, I think we're interested in drilling down deeper into kind of, any of the, any of these potential, you know, policy solutions that might help address the challenges that we that we found in our in our research, that parents are facing, and that providers face and trying to serve this population. And whether those are challenges at the system level with things like insurance and training or provider shortages. Or things at the provider level. So challenges that providers face in the office setting, you know, making adaptations to processes or equipment or the on the ground, practical solutions that providers face in serving this population. We have a lot of interest in continued research and continued support of implementing some of these potential policy solutions.

Kristina Malik 30:52

Thank you so much for your time today, Robbie and Kate and thank you to your team as well for advocating advancing the field of complex care and preventive health care.

Kate Honsberger 31:02

Thanks, it was really great to talk to you about it.

Robbie Dembo 31:05

Thanks so much for having us.

Kristina Malik 31:09

Thanks for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has the potential to be practice changing, that values patient and family engagement is relevant across disciplines and diagnoses and uses high quality or novel research methods. We invite you to join the conversation by suggesting the article that you would like to see discussed in this podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

Journal Club Article

NORC at the University of Chicago. Oral Health Among Children with Special Health Care Needs. Accessed August 4, 2025. <https://www.norc.org/research/projects/oral-health-children-special-health-care-needs.html>

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